NewStatesman

Genomics: the future of medicine

A revolution in diagnostics and treatment

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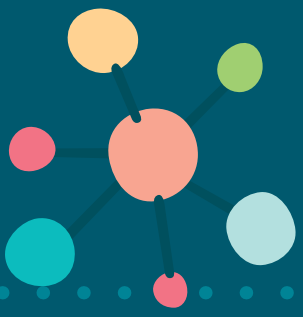
Genomic medicine: the facts

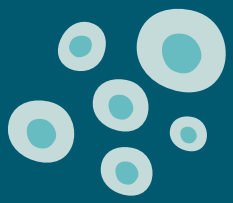
The UK is a world leader in the emerging discipline of genomics, using patients' genetic information to inform clinical care. But what is behind genomics and what opportunities does it offer?

The genome describes an individual's complete genetic code, comprising 20,000 genes and all

3,200,000,000

letters of your DNA.





Genomic medicine offers the chance to **revolutionise diagnostics**, deliver more personalised care, and help ensure the right patient gets the right treatment at the right time.

Advances in genomic medicine will also help **diagnose and treat** many forms of cancer.

Genomic approaches are likely to benefit patients with rare diseases, which affect 6% of the population, or

3 million people.

The NHS England Genomic Medicine Service will become the **first national healthcare service in the world** to offer whole genome sequencing as part of routine care. The NHS aims to sequence

500,000 genomes.

The UK is already a leader in genomics, and over the next 10 years the NHS will routinely offer **genomic testing to all cancer patients** to help identify the optimal treatments for cancer.

Figures from HM Government, Office for Life Sciences, and the chief medical officer

Genomics can help us build back better

If our shared experience over the past year has taught us anything, it is that human ingenuity can help overcome some of the greatest threats to our health, says James Bethell, Minister for Innovation.

As we look beyond the pandemic, it is imperative that we maintain this focus and keep exploring the scientific breakthroughs that will help us to live longer, healthier lives.

Genomics has a vital role to play. It helps us support the earlier detection and faster diagnosis of disease and gives patients the best possible chance of treatment and recovery.

Our country is breaking new ground in genomics and we are rightly recognised as a world leader. We have completed the world-first 100,000 Genomes Project, sequencing the whole genomes of people with rare diseases and cancers. This can be life-changing because it provides the most detailed information about genetic changes that can cause disease. Early diagnosis can have a massive, immediate impact on improving someone's chances.

The results of this project have been very encouraging. One in four people with a rare disease who joined the project without a diagnosis have now received one, and nearly half of the cancer patients were found to have cancer-causing changes in their genome, making them potentially eligible for clinical trials of new drugs.

We have also set up the pioneering NHS Genomic Medicine Service, and we have already seen a range of new services and tests becoming available for patients across England.

In 2021 we hope to go even further, offering whole genome sequencing initially to children with certain cancers and patients with a suspected rare disease. This will make the NHS the only integrated healthcare system in the world routinely offering this service.

We have big ambitions to go further as a global leader in genomics and have set out an aspiration to sequence 500,000 whole genomes in the NHS by 2024, with another 500,000 through the UK Biobank.

As this report sets out, the potential of genomics is not just to bring comfort and hope to patients, but to power the UK economy. Genomics will create high-quality jobs of the future right here in the UK and contribute billions to our economy every year.

We can transform the future of healthcare by offering care that is predictive, preventive and personalised, throughout this pandemic and beyond.

NewStatesman

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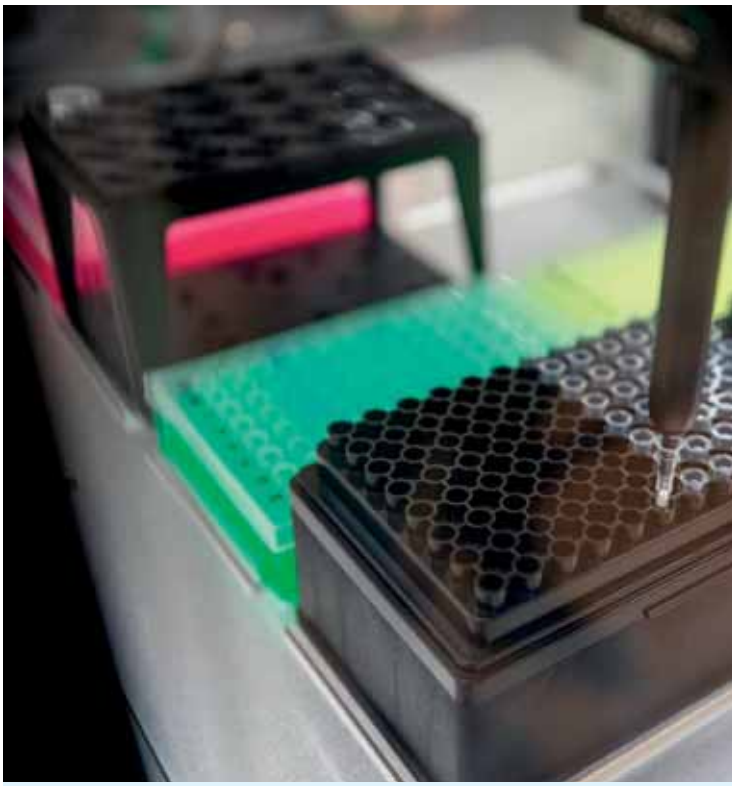
WINNER

First published as a supplement to the *New Statesman* of 22 January 2021.

Registered as a newspaper in the UK and US. The paper in this magazine is sourced from sustainable forests, responsibly managed to strict environmental, social and economic standards. The manufacturing mills have both FSC and PEFC certification and also ISO9001 and ISO14001 accreditation.
This supplement can be downloaded from: newstatesman.com/page/supplements

At an online event, sponsored by Lilly, experts and policymakers discussed the future of genomic medicine



The age of the genome

Late last year, the *New Statesman* gathered a panel of parliamentarians, clinicians, researchers, industry leaders and other experts to discuss the future of genomic medicine at an online round table sponsored by Lilly.

Chairing the discussion, health journalist Jacqui Thornton began by highlighting the UK government's ambitions in genomics and precision medicine, set out in a recent strategy document, *Genome UK: The Future of Healthcare*. Part of the strategy builds on the 100,000 Genomes Project, a major scheme that is sequencing whole genomes from NHS patients affected by rare diseases or cancer. "The overarching aim of this event," Thornton said, "was to ask what we need to do, as healthcare practitioners, innovators, system leaders, civil society, politicians and patients, to accelerate integration of genomics into routine NHS care."

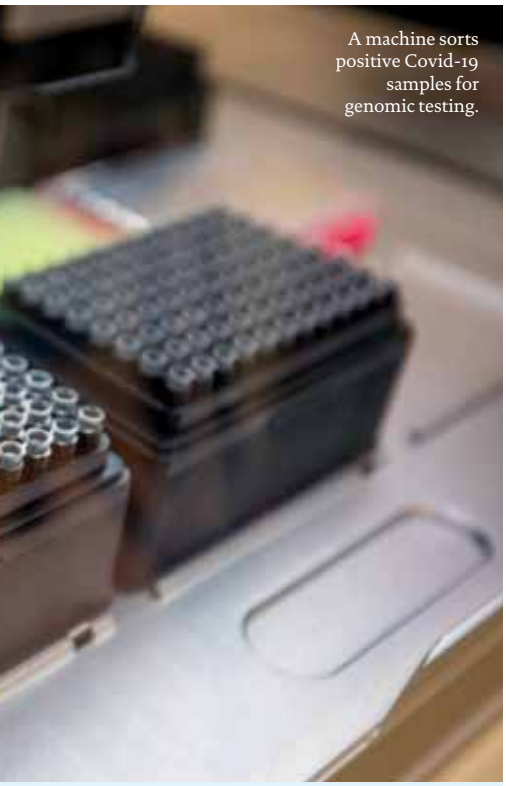
Emma Claeys, oncology business unit leader for the UK, Nordics and Ireland at Lilly, opened the conversation by sharing a real, on-the-ground example of the potential of genomic therapies for everyday patients. "A lung cancer patient," she told the group, "was lucky enough to receive precision medicine rather than undergoing chemotherapy, radiotherapy or surgery. Because of this treatment regimen she has been free from the ill effects of the more conventional modes of cancer care, to the point where she hasn't had to take time off work, and she made the decision not to tell her children about her diagnosis until she received her first positive news that her tumour was responding to treatment." The story served to illustrate "the power of science to change people's lives". Genomic medicine was "no longer science fiction", she concluded.

Later in the discussion, Professor Nicholas Turner, consultant medical oncologist at the Institute for Cancer Research, echoed Claeys. "The benefit for cancer patients is clear," he said. "And these therapies often are more effective than chemotherapy with substantially less side effects."

Responding, Dr Richard Scott, clinical director of Genomics England, gave the perspective of his organisation, which was established to deliver the 100,000 Genomes Project. "Genomics England," he said, was "just one part of a broader ecosystem." The government and the NHS were to be commended for "long-term thinking" and their "recognition of the importance of genomics".

"We've got representatives from across several organisations here, and with the establishment of new Genomic Laboratory Hubs throughout England the NHS is able to provide national coverage for genomic medicine. So this isn't just about precision medicine in one or two centres – this is about equity."

Following Dr Scott, the chair introduced Dr Mike Hubank, the head of clinical genomics at The Royal Marsden Hospital and London scientific director of the NHS North Thames Genomic Laboratory Hub, one of the genomic laboratory hubs praised by Scott. "We're in a good position," he told attendees. "All seven hubs are set up… and they're all at slightly different stages of implementation. But there are still some issues with consolidation. There are issues with getting samples in, and we have concerns about the level of training and staffing."



A machine sorts positive Covid-19 samples for genomic testing.

DOM THOMAS/GETTY IMAGES

Dr Alastair Greystoke, clinical lead for cancer at the Yorkshire, Hull and North East England Genomic Laboratory Hub, was able to provide a picture from a different part of the country. "We were bringing together three centres: Leeds, Newcastle and Sheffield," he explained. "We were used to working separately and had a very big geographical catchment area, with a large number of hospitals... so I think we started at a lower base [than the genomics lab in London]. But we're making significant progress."

Dr Susie Cooke, head of medical genomics at the Glasgow Precision Oncology Laboratory, was also able to give a snapshot of her work in Scotland, where health and social care policymaking is devolved to Holyrood. "It's quite a different picture in Scotland," said Dr Cooke. "The Scottish genetics laboratories that would deliver a genomic medicine service restructured in 2013. There are four centralised laboratories that are well established and operating smoothly in Scotland. What there isn't currently is a national genomic strategy to move from that kind of single gene testing into more comprehensive genomic profiling and a full genomic medicine service. The Scottish government hasn't made a decision or commitment on that yet."

Providing a parliamentary perspective, with insight from his time in government, the former minister for life sciences, George Freeman MP, set out the ambitious vision shared by health policy chiefs. As one of the driving forces behind the Life Sciences Industrial Strategy, Freeman expressed his view that genomic medicine was going to "totally shatter" the traditional model of drug discovery. "That is a huge challenge for the industry and a huge opportunity for the NHS," he said.

However, one of the barriers to achieving this broad vision, and translating national strategy into local implementation, is the need to upskill the workforce on this new science. Dr Anneke Seller, scientific director of the Genomics Education Programme at Health Education England, was keen to emphasise the importance of workforce training in making the genomics vision a reality. "We're working towards an implementation plan," she told the round table, "bringing together the genetics laboratory hubs, Genomic Medicine Service Alliance workforce leads... and education leads and a whole host of professionals to really try and prioritise [training and upskilling] as one of the most important areas in trying to get whole genome sequencing established."

Dr Mike Osborn, president of the Royal College of Pathologists, agreed that upskilling workforces was essential to the roll-out of genomics, and also raised other potential logistical logjams, including IT systems. "Our membership thinks genomics is fantastic," he said. "But sometimes lab results haven't fed back onto the computer system. That could be because it's a different computer system in a different hospital because that hospital hasn't quite amalgamated yet, for example."

Dr Philippa Brice, external affairs director at the PHG Foundation, a health policy think tank, was enthusiastic about the government's approach to supporting genomics so far: "We have the NHS, we have the research excellence and the infrastructure that's been established over recent years... The question now is about bringing those together so that they are delivering for clinical research."

One issue that was repeatedly raised was the question of building and maintaining patient and public trust in genomic medicine, particularly given the concerns around the collection and storage of patient data and the necessity of transparency. "Consent is key," said Professor Anneke Lucassen, professor of clinical genetics at the University of Southampton and founder of the Genethics Forum. "What we need to do is think about consent in innovative new ways because our traditional models of consent – signing a research consent form, or signing consent for an operation – aren't fit for purpose in this new model."

While barriers remain, there was consensus among attendees that the opportunities for genomic medicine are huge. What is needed is a coordinated effort around implementation that encompasses staff training, IT networks, delivery systems, data rights issues, and patient buy-in. The event delegates were confident that such barriers could be overcome and that the UK could remain a world leader in the field.

George Freeman gave a neat summary of the potentialities involved. "We're going from a world where one size fits all, there's 80 per cent failure rates, development takes 15 years and it costs £2bn," he said, "and then we're moving to a world where we can actually design drugs, starting not with an abstract theory, but with an app with a patient group...

"We can really embed discovery back in the hospitals, we can design for cohorts with a much higher degree of success without a ton of time and cost and risk – save the industry – build resilience, and you could actually make the NHS a fast-track test bed for tomorrow's personalised medicines."

A revolution in cancer treatment

Emma Claeys, oncology business unit leader for the UK, Nordics and Ireland at Lilly, explains how precision medicine is working to reimagine treatment

We are at a critical moment in healthcare. Twenty years since the decoding of the human genome, our understanding of genomics is converging with new breakthroughs in precision medicine in a way that promises to transform healthcare. For patients, the marriage of genomics and precision medicine promises highly targeted treatments with the potential to deliver improved outcomes faster, and in a way that is safer and more tolerable. The science of genomics is transforming how healthcare is delivered. Now we need to ensure our healthcare system is properly prepared.

In recent years we have increasingly come to understand cancer as genetically driven for many patients. Up to half of all cancers are thought to have genetic drivers or mutations that can be potentially targeted for treatment. Advances in genomic testing are beginning to transition us towards more personalised cancer care, moving away from a diagnosis based on tumour location (such as a lung) to a diagnosis (and treatment) determined by specific genetic markers. This approach is redefining cancer care, particularly for rarer or hard-to-treat cancers, and ensures the right patient gets the right treatment at the right time.

The UK has long been a global leader in genomics. The government is seeking to build on this legacy with the aim of developing the most advanced genomics healthcare system in the world. At Lilly, we welcome this approach, but we also know that ambition is meaningless if not combined with effective action.

We are keen to play our role in ensuring all patients can benefit from the latest breakthroughs in precision medicine. Connecting national-level ambition and local delivery is often complex, especially in an organisation the size of the NHS, but we believe there are four key building blocks for securing this exciting future for cancer patients.

Firstly, the benefits of genomics in cancer care need to be communicated more widely. Industry is ready to play a key role in this, working closely with third-sector partners and others, to grow a collective understanding of the role genomic testing can play in identifying patients who may benefit from new precision medicines.

Secondly, as the NHS embeds a new genomic testing model in England, centralising genomic testing in seven regional Genomic Laboratory Hubs, healthcare professionals must have confidence this reorganisation is working in the best interest of patients. Professionals should be engaged throughout this critical period.

Thirdly, as this new model of care is further integrated into routine practice, healthcare professionals will need continued opportunities to upskill in the practice of genomics and its relevance to patients and their families. Through its Genomics Education Programme, Health Education England has already begun excellent work in this area.

And finally, widespread adoption of genomics in the NHS can only happen with the right level of resourcing. That means every part of the genomics pathway, from sampling to logistics, must receive appropriate levels of central funding. Failure to support the system fully in all parts of the country could lead to a postcode lottery for patients. This cannot be allowed to happen.

At Lilly, we are excited for the future of genomics and precision medicine, and are impatient to get there. As these new therapies are increasingly integrated into the NHS, their full benefit will only be felt if we have the right foundations in place. If we want to ensure the future of healthcare is delivered successfully, the time to act is now.

A major step forwards

Developments in genomics mean it is an exciting time at Macmillan Cancer Support. These advances could allow some cancers to become predictable, treatable and preventable. At a time when Covid-19 is having a devastating impact on cancer care, progress in genomics is a positive step and will hopefully ensure cancer does not become the "Forgotten C" in this pandemic.

In practice, genomic services could mean earlier diagnosis and improved outcomes for people, and particularly groups that are at risk. Liquid biopsies can be used for detecting cancer instead of painful tissue biopsies and can make monitoring early signs of cancer recurrence less onerous for someone living with cancer.

The fear of recurrence and living with cancer is something we hear about a great deal at Macmillan through our support line. Some of the ways to monitor cancer can be unpleasant, but moving to something like liquid biopsies that are rapid, precise and in real time is a positive step for people whose lives are affected longer term.

Genomic information will increasingly assist clinicians in treatments. This means patients can be spared complex procedures, have less time in hospital and have a better quality of life through treatment. It also predicts how an individual will respond to drugs, informing the appropriate drug or dosage and enabling more personalised treatment for different cancers. Genomic data will also improve research, as it will give a greater understanding of the genetic basis for many cancers. This in turn will mean better access for patients to newer, targeted treatments.

The cancer population may start to look different due to genomics. The general population is growing and ageing, with more living with long-term conditions. The incidence of cancer is forecast to rise by 2 per cent each year, likely increasing the number of people living with treatable, but not curable, cancer – or with cancer as a long-term condition.

Developments in genomics could transform care, says Dany Bell, Macmillan Cancer Support's strategic advisor for treatment, medicines and genomics

Professionals will need good genomic literacy and to explain it in order to enable shared decision-making with patients. Macmillan nurses will also need some basic genetic counselling skills as part of their integral role delivering support through diagnosis, treatment and monitoring. The information and emotional needs of people living with cancer are likely to be higher depending on their understanding of genomics.

As genomics embeds in cancer treatment there may be other issues that professionals like Macmillan nurses have to grapple with. This could include managing expectations that people with cancer donate data for research, the uncertainty of not knowing what information genomics might reveal, and the trade-off between confidentiality and the potential benefits. Ethical considerations may become more prominent in decisions on disclosing information (for instance, to family members affected by test results) if people living with cancer do not want information disclosed.

Finally, there will need to be changes in how professionals work with new genomic services. Within the average clinic appointment to discuss treatments, the potential complexity and support someone might need to participate in shared decisions about genomic services may require longer appointments. Beyond this, a cultural shift is needed to embrace these new technological advances in genomics and their impact on care.

LILLY FOR BETTER SCIENCE

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